HIGHLIGHTS FROM 2021

LAUNCH OF OUR DISSECTING DEVICES WEBINAR SERIES

This free educational program profiled six products in the epilepsy technology space. The information reached more than 1,000 patients and caregivers.

12TH ANNUAL EVENING OF HEARTS & HUGS EVENT

Our annual gala was a hybrid event staged from Theater on the Lake, with supporters attending both in Chicago and by watching virtually from across the United States.

CO-HOSTED 2ND ANNUAL DEVICE ACCELERATOR COURSE

In collaboration with the Epilepsy Foundation, we facilitated a six-week virtual course to provide resources and experts for five new epilepsy device companies.

FIRST NETWORK TV CAMPAIGN ON ABC7 NEWS (CLICK)

PARTNERS AGAINST MORTALITY IN EPILEPSY CONFERENCE

Danny Did collaborated to plan and co-host a meeting for more than 250 bereaved caregivers, healthcare professionals, researchers and advocates to advance progress against mortality in epilepsy.

SUCCESSFUL "FIELD OF DREAMS" FUNDRAISING CAMPAIGN

We surpassed our goal of $35,000 and "sold out" our Field of Dreams for kids who face epilepsy.

FIRST ANNUAL PUSH UP CHALLENGE GOLF OUTING

We surpassed our goal of $35,000 and "sold out" our Field of Dreams for kids who face epilepsy.
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MEET DANNY
Danny Stanton was born on March 2, 2005. Danny died on December 12, 2009.

A wonderfully normal two years of development followed his birth as Danny joined his sister Mary Grace and his brother Johnny and took his place as kid number three in the Stanton family. He was, as his grandma Murtaugh dubbed him, the “little toughie” of the family. The kid was a scrapper who held his own as he established his place within his family. Even at two years of age, he had established himself—somehow, and in many ways—as an equal not only in terms of experiencing life, but also as one who brought experience to the lives of everyone in his family. Soon, Danny was no longer the youngest Stanton, as his brother Tommy came along when Danny was two.

It was at age two when Danny had his first seizure. His eyes rolled back and he shook. We did not know what was happening. We dialed 911 then rushed him to our next-door neighbor, who is a paramedic. Danny seized for almost 10 minutes. On that night, we had a battery of tests done at Children’s Memorial Hospital in Chicago. There was no known reason or cause found for Danny’s seizure. No injury, no trigger. We were told that sometimes seizures in children have no known cause and that kids often outgrow them. The experience was terrifying.

We left the hospital that night without any written information about seizures or seizure disorders, sans any mention of epilepsy or epilepsy organizations, and sans anything short of the feeling that we had fallen into a hole that had no bottom. Sudden Unexplained Death in Epilepsy, of course, crossed no lips and fell upon no ears. Danny began sleeping in bed with us after that first seizure.

Danny had a second seizure while sleeping just over a month later. After this second seizure, he had an MRI. Again, no underlying cause was found for his seizures. Danny was then put on a variety of medicines to control the seizures, and regular electroencephalograms (EEGs) were scheduled and performed. His neurologist determined that Danny had childhood seizure disorder. Still no mention of epilepsy, still no suggestion of outreach to epilepsy organizations, and still, of course, no mention of Sudden Unexplained Death in Epilepsy. What we were told was this: he’ll outgrow it, many kids experience this, we don’t know why it happens, maybe it’s “his normal.” How might life be different had a sophisticated and tough-minded doctor sat us down and said “let me tell you something that will shock you but that I am mandated both by my profession and by my personal sense of duty to inform you of . . . your son has epilepsy, and along with this diagnosis comes a plethora of safety issues that you need to become aware of…”

Danny’s daily behavior was completely normal. He continued to be athletic, inquisitive, engaging, social, and, more than anything, affectionate. As we continued meeting with Danny’s neurologist for regular check-ups, we became more and more comfortable with the idea that we were doing all we could for Danny and that we were on a clear and well-defined path. We were told that a slightly abnormal EEG might just be Danny’s ‘normal.’

After sleeping with us for a half a year, Danny began to return to his own bed. On hundreds of occasions we left our bed to check on him. We caught him twice more having a seizure in his sleep. We informed our doctors of every event.
We continued to trust and believe that we were doing all that we could. Birthdays, holidays, block parties . . . each month brought more punch to us as a family, and each day brought hugs from Danny: he’d tuck his arms into his own chest and then wait for you to surround his body with yours. He’d then nestle his head under your chin, take a deep breath, and let his exhale say that he had found the spot.

After a year of no known seizures, Danny returned again to his own bed. And then as he turned four and had gone without a known seizure for 18 months, we thought that our course of action had been successful and that his neurologist was right: Danny would, through medicine and time, outgrow his ‘seizure disorder.’ It was like a rebirth for us and for Danny.

On Tuesday, December 8, 2009, we took Danny for a scheduled appointment with his neurologist. He had a one-hour EEG done while sleeping, and we met with his doctor afterward. There was still abnormal activity showing up, but maybe a lesser amount than the previous EEG showed. We increased Danny’s dosage that day to accommodate a slight weight gain since his last visit.

Four days later, on December 12, 2009, we found Danny’s lifeless body in his bed at 7:15 am.

How many seizures did Danny have that we did not catch? We will never know. One thing we do know are the last words to ever fall upon that little toughie’s ears. They are the words whispered by his mom to Danny each and every night as she put him to bed: “I love you, sweet boy.” These words were always followed by three kisses: one to the forehead, one to the nose, and one to the lips. I love you, sweet boy.

Now life continues –in many respects– albeit without the soft bounce of one little boy’s feet upon the dirt of the Earth. Our Danny boy has entered a new phase, part of which is in the form of his organization, the Danny Did Foundation, which derives from the last line of Danny’s obituary: Please go and enjoy your life. Danny did.
Imperfectly, our son Danny had epilepsy. Tragically, our son Danny died from epilepsy. Specifically, Danny died from Sudden Unexpected Death in Epilepsy, also known as SUDEP. Graphically, Mariann found Danny dead in his bed one cold December morning two weeks before Christmas in 2009. Horrifically, we tried to resuscitate Danny that morning in front of his sister Mary Grace and his two brothers, Johnny and Tommy. Distressingly, we believed that we had been doing everything possible to care for Danny.

Through two years of treatment by medical professionals, we were never informed that Danny had epilepsy, and even though Danny suffered from seizures we were never informed that Danny could die from one of his seizures. We were never told about SUDEP. We were never given information about organizations that could educate and support us as we swirled through Danny’s seizure episodes.

And so when Danny died, we knew that he and that we had been robbed of the opportunities of a lifetime. An actual lifetime. And we were furious. And we asked each other in our bedroom on that morning in December – after we had returned home from the hospital were Danny’s body had grown cold atop of ours as we laid with him - we asked ourselves, “how could this happen?”

Part of our answer to that question has been the formation of the Danny Did Foundation, which we are nurturing and developing as if it were part of Danny himself, and together with so many other individuals and organizations, we are changing the perception of epilepsy and the outlook for those afflicted by epilepsy.

And so as one year closes and another begins, we look forward to new partnerships and to new alliances as we continue our work to enable access to seizure monitoring and detecting devices for families who cannot afford them, and to advance awareness of epilepsy and the risks that accompany it, including Sudden Unexpected Death in Epilepsy. Thank you for your participation and for helping to prevent another death caused by a seizure.

Mariann and Mike Stanton
Letter from the Executive Director

For all of the many challenges presented by the year 2021, it was nonetheless an exceptional time of perseverance and progress at Danny Did. Kurt Florian, the father of an adult daughter with epilepsy, began his new term as President of our Board of Directors. We launched a new initiative - called our “Dissecting Devices” webinar series - as a strategic response to fewer community interactions due to continued COVID-restrictions. Over our six webinars, we reached caregivers and patients, doctors and nurses, researchers and public health officials. As a separate means to bolster the seizure device pipeline, we held regular advisory meetings with device companies who turned to us to learn about patient and caregiver preferences.

In 2021, my nephew Danny would have been a junior in high school, experiencing a time of excitement when his curiosity, talents and friendships would have grown with the passing of another school year. Epilepsy impacts 1 in 26 Americans, and is second only to stroke among neurological disorders in Years of Potential Life Lost (YPLL). Each family who has lost a loved one to epilepsy knows how painful those lost years can be. The communication between medical professionals and their patients about risk of SUDEP, while improving, is still unacceptably low.

In September, I joined advocates from the Epilepsy Foundation of America to co-host a “device accelerator course” in which five startup companies in the epilepsy technology space gained access to resources during a six-week virtual course. The end goal of this project and much of our work is to create a healthy ecosystem in which patients and caregivers have ample, worthy choices when selecting an alerting device that can keep their loved one safe.

As we look back at this year, what makes us most proud is that our support for families in need has extended to all 50 states and 14 countries, support that many have described as life altering. As we grow to help more people, we encourage and appreciate your partnership. We are excited for what is to come, and driven to instigate more progress.

Tom Stanton
Mission
To advance awareness of epilepsy and Sudden Unexpected Death in Epilepsy (SUDEP), protect people with epilepsy, and prevent deaths caused by seizures.

Vision
To create a reality in which healthcare providers openly communicate SUDEP and all mortality-related risks with their patients or caregivers.
To elevate awareness of, and access to, technologies that provide early intervention and added safety when a seizure occurs.

Values
Family Love: Everything we do is in service of families;
Preparation: We help families prepare to protect their loved ones;
Hope: We hold hope for a brighter future;
Enjoyment of Life: Our work is meant to carry forward and spread Danny's joy for life.
ABOUT EPILEPSY

A seizure is a sudden behavioral change resulting from excessive electrical activity in the brain. Seizures may be provoked (also known as acute symptomatic; for example, a fever in a young child, drug intoxication or withdrawal, electrolyte imbalance) or unprovoked, resulting from a genetic, developmental, acquired (for example, head trauma, tumor, stroke), or an unknown cause.

When a person has two or more unprovoked seizures, they have epilepsy. An estimated 3.4 million Americans have active epilepsy, with up to 200,000 new cases diagnosed in the United States each year. Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults. Epilepsy impacts 65 million people worldwide and is a spectrum that spans more than 40 syndromes. Despite all available treatments, 30 to 40 percent of people with epilepsy continue to experience uncontrolled seizures. In two-thirds of patients diagnosed with epilepsy, the cause is unknown.

A report from the Centers for Disease Control and Prevention (CDC) indicates that the number of Americans with epilepsy is higher than ever. Epilepsy affects more people than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson’s combined – yet receives fewer federal dollars per patient than each of these. According to advocate group Citizens United for Research in Epilepsy, epilepsy costs the United States approximately $15.5 billion each year. The indirect costs associated with uncontrolled seizures are seven times higher than that of the average for all chronic diseases.
Seizures can sometimes be fatal from a range of causes, and no matter how the death is defined, every time it is a huge loss. There are numerous ways that a person can die stemming from seizure activity – drowning, an accident, head trauma, suicide, or status epilepticus. Another category of epilepsy mortality is Sudden Unexpected Death in Epilepsy, or SUDEP. SUDEP is the most common category of death in epilepsy. SUDEP is just that: sudden and unexpected. The most recent research shows that a case of SUDEP occurs in 1 in 1,000 people with controlled epilepsy, and for 1 out of 150 people with uncontrolled epilepsy.

The Danny Did Foundation pledges to shine a light on SUDEP for as long as is necessary to achieve major progress in awareness and in the advancement of preventative measures.

**WHAT DEFINES A CASE OF SUDEP?**

SUDEP is not a cause of death but rather a category of death. A death is referred to as SUDEP when a seemingly healthy person with epilepsy dies unexpectedly and no clear reason for the death can be determined. In most cases, an autopsy is required to rule out other causes of death. The most common criteria used to determine whether a death is due to SUDEP are:

- The person has epilepsy, which is defined as recurrent unprovoked seizures.
- The person died unexpectedly while in a reasonable state of health.
- The death occurred suddenly and during normal activity (often during sleep).
- An obvious medical cause of death could not be determined at autopsy.
- The death was not the direct result of status epilepticus.
2021 YEAR IN REVIEW

Danny Did Foundation
ADVANCING AWARENESS

For a collective reach of more than 8 million people!
Our practical impact is to enable access to seizure alert devices for families in need. These systems provide added safety for patients, and enhanced peace of mind for caregivers.
STORIES OF IMPACT
Wadler Family, New York

Your grant is unbelievably generous. Especially during these difficult times during the COVID-19 crisis. We are very appreciative of the Danny Did Foundation. You have given us a sense of security like no other. Thank you so much!

Ann, West Chester, Pennsylvania

I want to thank Danny Did for my son Mike's InsyPre smartwatch. It is such a relief to know he is okay when I can't be with him. He feels much more confident knowing he will have someone to check on him if needed. It's great having the GPS. He can now walk his dog where he wants without checking in with me. Today is Mike's 54th birthday, and I no longer have to treat him like a child. I'm forever grateful.

Mbong Family, Detroit, Michigan

I just wanted to tell you that the SAMi monitor is amazing and has caught every seizure my daughter has had since we got it. And because she has so many different kinds, being able to show the doctors the recordings is amazing. She has been doing very poorly unfortunately, and just got released from her 19th hospital stay this year. This time in the ICU again, but I wanted you to know that we are very glad to have this device for her.
I am a doctor who attended the SUDEP symposium that Danny Did Foundation was a partner to with the Child Neurology Foundation. Listening to the speakers there completely changed the way that I talk with my patients about the risk of sudden death, and I now understand the importance of having the conversation with EVERY family. Since adjusting my communication on this topic, I have noticed an unexpected benefit: my patients are more compliant with their medications and more open about breakthrough seizures. I wish I had thought of this sooner! I have been using the materials provided at the symposium, and I will be ordering more soon.

For its work on SUDEP education and epilepsy care, the Danny Did Foundation is an outstanding organization and a Chicago jewel!
Educational Presentations in 2021

- Epilepsy Canada and Affiliates
- Spanish Language Webinar with EF of Colorado
- Medical Students at the University of Illinois
- HOSA Future Health Professionals
DO IT FOR DANNY FITNESS CLASS
We took the action outside with a bootcamp fitness class in La Grange, Illinois. Led by FitGive, more than 100 participants worked up a sweat for kids who face epilepsy.

ICE DONS SKATE FUNDRAISER
The entire hockey program from Notre Dame College Prep came out to skate 100 laps to raise funds to benefit Danny Did.

PAT MCGANN'S PODCAST LIVE FROM ZANIES
This laugh-out-loud event hosted by comedians Pat McGann and Jim Flannigan was a fundraiser for Danny Did. DDF Co-Founder Mike Stanton addressed the audience before the show.

1ST ANNUAL PUSH UP CHALLENGE GOLF OUTING
Lead by Co-Captains Kevin Cohen and Nathan Wysocki, this sold out event raised more than $100,000 in Hawthorn Woods, IL.

12TH ANNUAL EVENING OF HEARTS & HUGS
Our first ever hybrid Hearts & Hugs gala welcomed guests to Chicago's lakefront both in person and virtually from around the U.S. to raise funds for families facing epilepsy.
Danny Did Launches First Ever TV Campaign on ABC7

Epilepsy Community Says Chicago Bears Justin Fields Revealing His Condition is a Landmark Moment

Chicago Tribune

Former NFL Player With History of Seizures Dies Suddenly at 33

ESPN

Team Danny Did Runner Honors Late Friend
2020-21 was difficult on everyone in so many ways. For some families, the COVID-19 pandemic added another layer to their grief. We worked hard to keep our community connected, and helped families to make it through challenging times.

Here's What We Did

- Distributing multiple surveys to collect patient and caregiver feedback about the impact of COVID on the epilepsy community.
- Producing a “coping with grief during external adversity” webinar panel, offering free resource and support to the community.
- Donated masks to the epilepsy unit of Comer Children’s Hospital at the University of Chicago.
- Promoted access to free Keto diet supplies from a company called Trumacro.
- Made special exceptions within our device grant program to extend our ability to help.
- Hosted two virtual events as new ways of fundraising: a comedy night, and yoga class. Each welcomed attendees from across the U.S.
CO-FOUNDERS

Mike grew up in a family of 10 in Chicago’s Rogers Park neighborhood. After graduating from Loyola Academy, he earned his college degree from Northwestern University. He has worked in law enforcement for more than 20 years. He and his family live on the northwest side of Chicago.

Mariann grew up near Chicago’s south side in Oak Lawn, Illinois. Mariann attended Mother McCauley high school, where she was a star basketball player before going on to Loyola University as a four-year scholarship basketball player. She earned a degree in English from Loyola and then went on to earn a Master’s degree in Education from DePaul University. Mariann is a high school teacher in Chicago.

Mike Stanton, Co-Founder

Mariann Stanton, Co-Founder
Tom became Danny Did’s founding executive director in 2010. He remembers many endless summer days and nights playing with Danny and his siblings on Leona Avenue. Tom leads the communications and fundraising efforts for Danny Did, and works to expand their collaborations and impact in the larger epilepsy community. Tom holds a journalism degree from the University of Dayton, and a master’s degree in Public Policy from DePaul University. More than anything, Tom gained happiness from the love Danny gave by way of lots of hugs. He is thankful to have the chance to keep Danny’s spirit alive through service to Danny Did.

Tom Stanton
Executive Director

Mary has been a part of the DDF staff since 2010. However, her relationship with Danny’s family began when her young sons, Brenden and Charlie, spent years playing sports with the Stanton children. Mary leads Danny Did’s efforts with family support, event planning, and volunteer coordination. She earned her Bachelor’s of Science at Northern Illinois University and her Master’s in Human Resources at Loyola University in Chicago. Mary considers it an honor to serve at Danny Did, and the Stanton family is most grateful not only for her friendship, but also for the wonderful buddy that Charlie was to Danny.

Mary Duffy
Assistant Executive Director

Cathy is the third member of the DDF staff. Her diverse duties including leading interactions with the thousands of families that reach out to Danny Did annually. She has a long history as a small business owner and family advocate.
Julie is a media sales executive and her career path has featured sustained success at some Chicago's largest radio stations. She is currently an executive at Prime Time Media, where she utilizes her experience and relationships to connect the Danny Did Foundation with a variety of awareness platforms and opportunities. Julie is a graduate of Purdue University, and lives in Wilmette, IL with her husband and their children.

Lynn is an attorney specializing in commercial real estate development, land use and zoning. Lynn has also taught real estate and zoning classes at the University of Richmond Law School and the Loyola University of Chicago Law School. She holds a BA from Miami University, an MA from Xavier University and a JD from Loyola University of Chicago. She and her family live in Winnetka, IL.

When the eldest daughter of Tracy and Brian Jablonski was diagnosed with epilepsy and a brain tumor in 2015, they learned about the Danny Did Foundation. She has since become an advocate to spread awareness about epilepsy, SUDEP, and the technologies available. Tracy is a graduate of St. Francis University. She and her family live in LaGrange, IL.

Dan advocates as a person who has epilepsy himself. A former Illinois state senator, he has devoted his adult life to public service. While in office, Dan steered passage of the "Danny Stanton SUDEP Act", to mandate reporting of SUDEP cases to a national registry. He now serves as the CEO of ChildServ, a nonprofit that helps at-risk children build better lives. Dan graduated from the University of Illinois and received a Masters of Arts Degree from DePaul University. He and his family live in Park Ridge, IL.

Jerry is a physician at the University of Illinois College of Medicine at Chicago. He first started working with Danny Did as an executive board member of Northwestern University’s Dance Marathon, where he successfully managed an effort that raised $1,214,632. Jerry also holds a B.A. from Northwestern and an M.S. in from Georgetown. He is a native of Buffalo Grove, IL.
Doug Bruno has more than 700 career victories as head coach of DePaul University’s Women’s basketball. In addition, as a coach for USA Basketball, he coached two different teams to Olympic Gold Medals. Doug was a founding board member for the Danny Did Foundation. He now serves as a member of our Emeritus Board. His family knows the challenges of epilepsy.

Josh is an analyst for JPMorgan Chase. His support for Danny Did includes strategy planning, marketing expertise and service as our DDF board treasurer. He holds an MBA from Northwestern University’s Kellogg School of Management.

Diane has hosted several fundraising events for Danny Did, with several featuring her role as a zumba dance instructor. This year she completed a 26.2-mile swim-a-thon to benefit kids who face epilepsy.

John owns and operates several Chicago area businesses, including Theater on the Lake, a premier dining and event space located on Chicago’s lakefront in Lincoln Park. He is active in all forms of philanthropy and specializes in fundraising and development.

Kari is a family nurse practitioner who brings a valuable healthcare provider perspective to the Danny Did board. She has also served as Co-Chair of our annual Hearts & Hugs gala, and is a repeat member of Team Danny Did. His family knows the challenges of epilepsy.

With his wife Mariann, Mike is the co-founder of the Danny Did Foundation. His vision for keeping Danny’s spirit alive in the world through the work of the foundation is a guiding light. He is a repeat member of Team Danny Did. He does regular public speaking engagements on behalf of the foundation.

Kari Heideman - Secretary

Danny Did Foundation
Caroline has worked at DePaul University for over 15 years and manages employer relations for the Career Center. Caroline was diagnosed with epilepsy when she was a teenager. Her personal experience has led to her desire to raise awareness of epilepsy. She holds a BA from the University of Dayton and an MS from DePaul University. She and her family live in Chicago, IL.

Jeanine has spent 25 years in the real estate industry, both as a broker and an executive. With her daughter Erin McShea, she oversees The McShea Group at @properties. Jeanine is mother to two adult children with epilepsy, both who serve on the Danny Did Young Professionals board. She holds a bachelor’s degree from Winona State University, and lives in Chicago with her family.

Jennifer is a mother, wife and registered nurse in Decorah, IA. She advocates in honor of her son Brendan, who died from SUDEP in 2017 at age 19. Among her many forms of advocacy, she has run multiple marathons as a member of Team Danny Did.

Kurt is a lawyer and a past executive director for the Epilepsy Foundation of Greater Chicago. He advocates in honor of his adult daughter, and the many families he has supported over the years. He and his wife Linda live in Wheaton, IL.
Our Danny Did Associate Board integrates young professionals into the varied programs and campaigns of the Danny Did Foundation. Through volunteer activities, social and fundraising events and networking opportunities, this Board encourages the next generation of leaders to engage in our mission to prevent deaths caused by seizures.

KATIE ONSAGER, CO-PRESIDENT
JEN STONER, CO-PRESIDENT
KRISTIN MCSHEA
ALEXIS FLORES
LAUREN KNEPPER
NATALIE KNEPPER
MIKE WOJTYCHIW
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PATRICK LAZARRA (MINNEAPOLIS)
ROSS GORDON (NEW YORK CITY)
DIAMANTAPANFORD (CLEVELAND)
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NORTHERN ILLINOIS

ALLISON AUSTIN
NORTHERN VIRGINIA

MISTY & STEPHEN PHILLIPS
NORTH CAROLINA

SHERRI & BRAD NEWMAN
WASHINGTON, D.C.

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KANSAS

KALEENA FITZSIMMONS
CHINO, CALIFORNIA

SCOTT AND LANA FREY
INDIANA

KARI AND DENNIS KNAPP
TWIN CITIES, MINNESOTA

STEFANIE AND MARC MINGLE
SOUTHERN CALIFORNIA

CINDY MITCHELL & FAMILY
SOUTHERN CALIFORNIA
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LEMON, ILLINOIS

PETTersen FAMILY
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GREATER PHILADELPHIA

SASHA PINA
LAS VEGAS, NEVADA

TANISHA GRAVES
VIRGINIA

SYLVIA PALM
MARYLAND

JULIE AND JOHN
BEZOLD
JACKSON, TENNESSEE
We Can't Do It Without You!

**SUPPORT DANNY DID**
1. Make a Tax Deductible Donation at Dannydid.org
2. Utilize your company match program after you donate.
3. Shop on AmazonSmile to Benefit Danny Did
4. Purchase DDF gear at Dannydid.org
5. Donate auction Items

**ADVOCATE WITH DANNY DID**
1. Volunteer at a DDF Event
2. As your doctor to talk about SUDEP prevention and research
3. Share the Seizure Safety Quiz at your School
4. Lead a “fan raising” Social Media Campaign

**GET INVOLVED WITH DANNY DID EVENTS**
1. Organize and Host your Own Fundraising Event
2. Sponsor a Danny Did Event
3. Coordinate a Seizure Safety Presentation at Your School
4. Join Team Danny Did

**PARTNER WITH DANNY DID**
1. Medical Professionals: Help Us Talk About SUDEP
2. Families: Assist Danny Did’s Outreach to Doctors
3. Device Companies: Tell us about your technology

Find out more at Dannydid.org/get-involved
Please go and enjoy your life. Danny did.